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Challenges to Telehealth

What Was Learned from Families of Children with Neurodevelopmental Disorders



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KEYWORDS

- Neurodevelopmental disorders • Telehealth
- Children with neurodevelopmental disorders • Telehealth in vulnerable populations

KEY POINTS

- Telehealth visits have provided a safe alternative to in-person visits during the COVID-19 pandemic.
- Children with neurodevelopmental disorders can benefit from telehealth utilization but may experience some challenges.
- Racial disparities exist in telehealth accessibility.

Abbreviations

NDD

neurodevelopmental disorders

INTRODUCTION

Coronavirus disease 2019(COVID-19) has affected all facets of life since its beginning. Healthcare delivery has not escaped the impact. Hospital and clinician shift to limit exposure and utilize limited resources acted as a springboard for rapid growth of telehealth utilization. One source reports an increase of 2938% since the start of the pandemic.¹ The increase has brought both benefit and barriers to care. Efficient, evidence-based care is important to maximize health outcomes in any situation. Although telehealth is not a new phenomenon, the data to support evidence-based telehealth care to reduce the barriers is not widely available.

This article will examine the challenges to telehealth as experienced by children with neurodevelopmental disorder (NDD) and their families. The children were all patients at a pediatric hospital in the United States during the first year of the pandemic. It will also provide recommendations for providing equitable care through telehealth to this vulnerable population.

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HISTORY

In a metropolitan hospital serving the pediatric population, COVID brought changes familiar to other healthcare facilities worldwide. Elective procedures were canceled. Preventative care was rescheduled. And in person visits were significantly reduced to those deemed necessary.

The divisions of the hospital serving children with NDD were impacted by the shift. For families of children with NDD challenges with canceled and rescheduled appointments was just a start. Home health nursing was limited in many cases to reduce risk of exposure. Therapeutic services including physical, occupational and speech therapy were placed on hold. When telehealth became available, for many it may have been viewed as an additional challenge to navigate.

Legislation at the federal and state levels supported expansion of telehealth services through policy change on allowable providers, location and reimbursement.² Within a 2-month period the shift to utilize telehealth visits in many clinics was carefully and rapidly rolled out in an attempt to meet the healthcare needs of its patients. As reliance on telehealth increased, patient feedback was needed for future planning.

BACKGROUND

Children with Neurodevelopmental Disorder

Children with neurodevelopmental disorders (NDD) are diagnosed as having an impairment of the central nervous system caused by genetic, metabolic, toxic or traumatic factors.³ Common diagnoses include cerebral palsy, autism spectrum disorder, Down Syndrome, traumatic brain injury and multiple genetic syndromes. Children with NDD frequently have multiple diagnoses and are dependent on medical technology for some component of their lives. This technology could include nutrition, respiratory or ambulatory support.

Children with NDD have varying levels of cognitive ability. Many have limited to no verbal communication skills. These children may ambulate independently or rely on assistive devices to move around.

This population requires care by an interdisciplinary team that may include therapists, advanced practice registered nurses, physician assistants, physicians and social workers. This team is in addition to the team of teachers and support personnel that address their medical needs during the school day. Well-rounded care of these children results in not only increased monetary cost, but indirect costs related to the time involved.

Children with NDD represent less than 2% of the children in the United States. Yet costs related to their care has been documented to be as high as 143% of costs related to typically developing children vastly outweighing the medical costs for the other 98% of US children.⁴ It is imperative that clinicians provide quality care while remaining efficient stewards of healthcare resources.

Caregiver Stress

Parents of children with NDD transport their children to multiple appointments on a routine basis. This necessitates the caregiver juggle the schedule of the child with NDD and often that of other children, family members, as well as their own employment requirements. A study by Bentenuto and colleagues demonstrated the increased stress levels experienced by parents of children with NDD before and during the pandemic.⁵ Stress can emanate from care, lost sleep, financial burden, lack of social and emotional support and job performance.⁶

As previously stated, families of children with NDD report a higher level of stress than parents of neurotypical children at baseline. Concern existed for the impact of COVID-19 to magnify that stress. A scoping review examined the challenges caused by COVID-19 for families of children with NDD. The resulting themes included challenges with behavioral issues, disruption of daily activity and challenges with existing resources to assist families.⁷

Children with NDD have varying levels of dependence on caregivers throughout the day. Some are dependent on others for all activities related to daily living. During the pandemic, families balanced COVID-19 exposure risk against shouldering the care previously shared by a team of family and paid providers. Families closed their doors to people outside their home to maintain safety. Some studies indicated the isolation and increased care burden experienced by the families not only increased parental stress but had a negative impact on behaviors of the children.^{7,8}

Education was also negatively impacted. The patients and families lacked the support, training and knowledge available in the schools to help their children accomplish their schoolbased tasks.⁹ Pasca and colleagues demonstrated almost 40% of patients in a study reported challenges with completing schoolwork.⁹ Parents were acting in the role of parent, nurse, aide and teacher. With the increased workload they were unable to adhere to the child's routine schedule. This impact of the disruption in routine was demonstrated by some with an increase in disruptive behavior. It was also demonstrated in some with a decrease in family functioning.¹⁰

Telehealth

Telehealth is defined as the use of electronic information and telecommunications technology to provide care from a distance. Telehealth delivery can vary and can include both audio-only and combined audio-video visits.^{11,12} Telehealth was first recorded in the early 20th century when data was transmitted via the telephone wires.¹³ It advanced gradually each decade and then exploded during the pandemic.¹³

Telehealth can be used to deliver routine and episodic care through a variety of mechanisms including tablets, computers, and telephones. Telehealth has been provided through both 1:1 and in a hub and spoke format. In the hub and spoke format, a patient goes to a physical location managed by a technician or other member of the health care team. The team member may utilize equipment that transmits information or images to a clinician at a satellite location or hub. This enables the patient to be seen by a specialist whose distance or schedule prohibits an in-person visit.

Telehealth and the Impact on Children with Neurodevelopmental Disorders

During the pandemic the use of telehealth decreased potential exposure of the patient and healthcare staff to COVID-19. Caregivers of children with NDD avoided the arduous process of transporting a nonambulatory child and the necessary lifesaving equipment such as portable ventilators and wheelchairs. When possible this was replaced with use of an electronic device to engage with their healthcare team, saving time and travel related expenses.

Published studies on telehealth use during the pandemic have reported up to 70% of parents of children with NDD used telehealth during the pandemic.¹⁴ In the same study, nearly 50% of those surveyed reported overall satisfaction. Only 30% thought the services worked well for their children.¹⁴ Details on the discrepancy between overall satisfaction and what worked well were not available.

Telehealth benefits were observed by clinicians caring for patients with NDD. The Society for Developmental & Behavioral Pediatrics cited improved access, increased naturalistic observations, reduced travel challenges and cost reduction as reasons

supporting telehealth.¹⁵ Children with NDD can experience increased stress when in unfamiliar environments. Clinician ability to observe patients in their homes through telehealth offered a different perspective to develop a diagnosis and resulting plan of care. Tools have been and continue to be developed and validated to improve the diagnostic process via telehealth.¹⁶

Caregivers also reported benefits related to telehealth utilization. Families noted the improvement in travel time and decreased fuel costs avoided with telehealth. A study demonstrated 30% of families reported a time savings of over 3 hours related to reduced travel with telehealth.¹⁷ Caregivers also reported appreciation that some services were able to continue via telehealth, avoiding a regression in skills.¹⁸

Benefits to telehealth could also serve a dual role as a barrier. A child's familiarity with their home surroundings sometimes contributed to distractibility and interfered with engagement during the exam.¹⁶ Telehealth visits also lacked the hands-on assessment needed to properly diagnose causes of change in function or discomfort. Challenges exist in assessing some children with NDD secondary to inability to assess muscle tone and coordination.¹²

Parents reported concern that the online environment impacted the child's ability to engage. Additionally, caregivers reported challenges with multitasking during the appointments related to managing care of multiple children in the home.¹⁸ Some therapy sessions were beyond what a single caregiver at home could manage. A single adult in the home would have challenges positioning the child while also trying to adjust the camera.¹⁹ The literature also discusses caregivers experience of challenges accessing technology.¹⁷

Broadband Access

Current estimates on U.S. households lacking access to high-quality broadband varies widely between 19 million to 42 million.^{12,20} Correlations between household access to an electronic device and household income have been documented.²⁰ Families experiencing increased stress and decreased resources during the pandemic may not have had the ability to access a device and/or internet access to facilitate a telehealth visit. There were multiple reports of families driving to a local school or library to access Wi-Fi from the parking lot.

Historically, marginalized populations disproportionately lack access to broadband either through internet access itself or access to a useable device. According to 2015 US Census data Black households were least likely to own all types of electronic devices and/or have broadband access.²⁰ Marginalized groups were also more likely to only have access to handheld devices verses a tablet or laptop computer.²⁰

METHODS

Context

A survey requesting patient feedback on telehealth was developed and distributed through email following their telehealth visit. Data on patient perspectives of challenges with telehealth was deemed important in quality improvement related to telehealth. The survey consisted of 30 questions on general experience and ease of scheduling, care provided by staff and challenges related to use of telehealth. Information on gender, race, ethnicity, geographic location, provider type, primary diagnosis, language, interpreter use and reason for visit were captured.

Ethical Considerations

Division specific data was distributed automatically to management. The author requested and received IRB approval to review the data specific to patients with NDD. The study was deemed exempt.

Measures

The survey used a Likert scale of 1 to 5 to indicate respondents' level of agreement with a particular statement. Zeroes were used to indicate a response was unchecked to a specific question, despite answering others. Dashes were used to record lack of response to a specific record.

The survey questions related to perceived challenges to use of telehealth can be grouped into five categories. The categories are listed in **Table 1**. It also provides a list of the questions on perceived challenges.

Although the survey was used hospital wide, this discussion focuses on the responses by clinics primarily serving the needs of children with NDD including a clinic focused on managing developmental behavioral pediatrics, the interdisciplinary cerebral palsy team and a complex healthcare clinic that serves as a primary care home for children with NDD. The responses were collected over a 6-month period.

| Table 1 | |
|---|---|
| Survey questions on perceived challenges of telehealth | |
| Perceived Challenges Legend | |
| <i>Accessibility/Technology</i> | |
| 1 | Challenges finding internet access |
| 2 | Challenges finding a suitable digital device (such as smartphone, tablet, computer) |
| 3 | Trouble logging into MyChart |
| 4 | Trouble starting the video call (Zoom) |
| 5 | Not sure how to carry out a telehealth visit |
| 6 | Need for translation services |
| 7 | Not able to directly get written records (such as medical record and educational materials) |
| <i>Comfort/Privacy</i> | |
| 8 | Finding a quiet, private place to carry out the visit |
| 9 | Not comfortable with physical exposure on camera over the video visit |
| <i>Quality</i> | |
| 10 | Worried about the quality of telehealth visits |
| <i>Financial</i> | |
| 11 | Concerns about whether the visit would be covered by insurance |
| <i>Other</i> | |
| 12 | COVID-19 related impact on scheduling a visit (eg, no childcare, changing work schedule) |
| 13 | Concerns about policy |
| 14 | Other |

RESULTS

Participants

Survey data from a 6-month period of distribution was reviewed. Three hundred ninety-eight responses were received from families and caregivers for children with NDD seen for medical, behavioral, and nutritional needs. Primary diagnoses for the visits included cerebral palsy, attention deficit hyperactivity disorder (ADHD), intellectual disability, constipation, upper respiratory infection, global developmental delay, autism spectrum disorder, avoidant restrictive food intake disorder (ARFID), anxiety, mitochondrial metabolism disorder, trisomy 21, feeding difficulties and disruptive behavior.

Over half of the respondents, left multiple questions unanswered. The email request was the singular opportunity to respond to the survey. There were no in-person or paper surveys offered in the clinic setting. There were no follow-up inquiries based on survey results. [Table 2](#) lists demographic data.

Over the 6-month period of data collection, 176 (44%) of the visits were completed by physicians, advanced practice registered nurses and psychologists. Most patients with NDD are managed by multidisciplinary teams. Additional clinicians that provided

| Variable | N (%) |
|---------------------------|----------|
| Gender | |
| Male | 288 (72) |
| Female | 110 (28) |
| Race | |
| Asian | 10 (3) |
| Black or African American | 55 (14) |
| Multiple Race | 37 (9) |
| Unknown | 6 (1) |
| White | 290 (73) |
| Ethnicity | |
| Hispanic or Latino | 18 (5) |
| No information | 7 (1) |
| Not Hispanic or Latino | 373 (94) |
| Primary Language | |
| Arabic | 2 (<1) |
| English | 371 (93) |
| Other | 12 (3) |
| Somali | 2 (<1) |
| Spanish | 11 (3) |
| Age (Years) | |
| 1–3 | 49 (12) |
| 4–6 | 60 (15) |
| 7–12 | 172 (43) |
| 13–18 | 102 (26) |
| >19 | 15 (4) |

COUNT OF DEVICES USED FOR TELEHEALTH VISIT

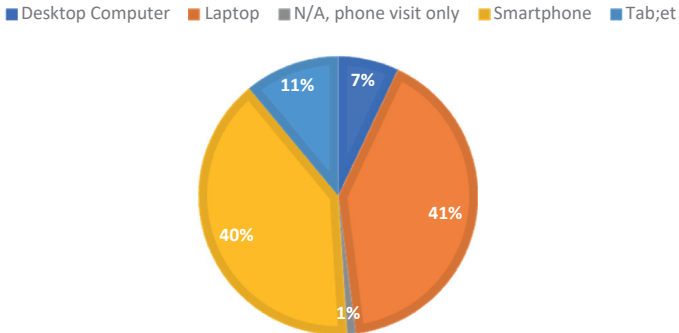


Fig. 1. Count of devices used to access telehealth.

care included social workers, dietitians, behavioral health technicians, therapists, counselors, fellows, and interns. All visits analyzed were completed using the Zoom video conferencing platform to ensure privacy and security; except two that were completed via phone. Reasons explaining the switch to phone from a video visit were not captured in the survey.

Numerous devices were used to complete the visits. Slightly more families reported use of a smartphone than a laptop. Details are provided in [Fig. 1](#). Although expansion in reimbursement temporarily allowed for limited use of telephone only visits, the vast majority of visits included audiovisual input.

Challenges to Telehealth

The survey included 17 questions specifically targeted at telehealth use. As many as 58% of respondents left multiple questions unchecked. There were no reported challenges with survey completion recorded in the data set. [Fig. 2](#) describes the frequency of reported challenges by previously stated categories.

Most reported challenges were accessibility and problems with technology. [Fig. 3](#) represents results from questions specifically addressing those challenges. When examining the responses in their entirety, challenges with accessing MyChart, the patient portal used to access and begin their visits, was the most reported difficulty. This was followed closely by challenges using the Zoom audiovisual platform.

Differences were noted with some responses when analyzed by race and ethnicity. This analysis was relevant for planning future use of telehealth and addressing Social Determinants of Health. Detailed breakdown for challenges with internet access, finding a suitable device and accessing MyChart are presented in [Figs. 4–6](#).

Finding a quiet, private place to carry out the visit was a challenge for 13% of respondents. The exact location of the patient and family during the visit was not captured in the survey. Only 1% of families reported discomfort with physical exposure on camera.

Only 5% of respondents reported concern about insurance coverage of the telehealth visit. Data on patient insurance status was not collected as part of the survey. Neither was insurance type.

Three percent of respondents were concerned about immediate access to written materials. These could include after visit summaries and patient education. All patients using telehealth had MyChart electronic access that may have provided some ability to print educational materials.

Ninety-two percent of respondents agreed that telehealth improved access to healthcare. Of the respondents that did not think access was improved, less than 1% strongly disagreed. Details on why respondents disagreed access was improved was not captured. Data on respondents' opinion on the quality of telehealth to In-Person is detailed in [Fig. 7](#). Analysis by provider type followed the trend of the overall group.

Most respondents reported they would consider use of telehealth in the future. [Fig. 8](#) represents a detailed analysis. Data on why respondents would not use telehealth in the future was not available in this data set.

DISCUSSION

The survey on the telehealth experience was distributed hospital-wide to all patients participating in a telehealth visit. The focus of the author was to examine the challenges experienced by patients and families of children with NDD as they learned to engage with their healthcare team via telehealth. The daily routine of these families is important, and change can result in negative behaviors.¹² Review of the responses revealed 79% had a favorable experience and would agree to use telehealth again.

Challenges were reported more frequently in areas related to accessibility and technology than any other question group. The challenges experienced by this patient population is congruent with that found in the emerging literature.¹⁹ Challenges finding internet access, a suitable device and accessing the patient portal (MyChart) were the most frequent barriers to care reported by the families.

Additionally, concern exists for racial and ethnic disparities in telehealth accessibility based on the responses. Asian respondents reported difficulty with internet access at rates 3 times that of white respondents. Black or African American respondents reported challenges with internet access at twice the rate of white respondents. This is consistent with disparities noted in the literature.²⁰

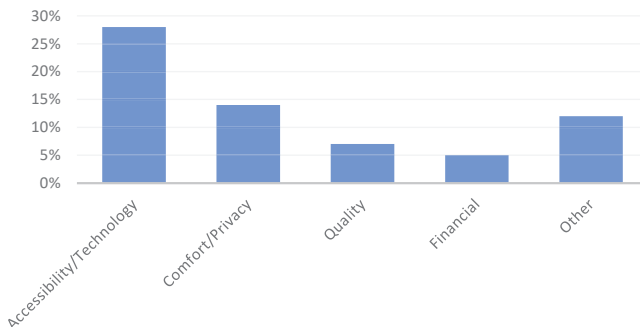


Fig. 2. Challenges by category.

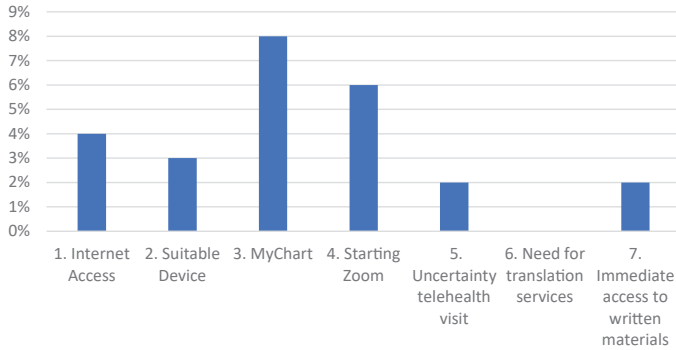


Fig. 3. Challenges to accessibility/technology.

Similar differences were observed in challenges accessing a telehealth suitable device. Seven percent of African Americans agreed they had difficulty accessing a telehealth suitable device. Only 3% of families of white children reported challenges. Zero percent of persons identifying as Asian reported challenges with access to a suitable device. Although the overall percentages of reported difficulties are small, the differences are notable. Fifty percent of African American families reported use of a smartphone to complete the visit. Thirty-nine and 37% respectively of Hispanic and white families reported smartphone use. There was not a question asking the respondent if the handheld device was their only option.

It may be beneficial to develop routine measures to assess broadband access or challenges with telehealth use for persons with multiple recurring appointments. These results reinforce the literature that emphasizes the need to increase access to broadband and suitable devices for children with NDD.¹⁵ Further research is needed on the best way to assess the technology needs.

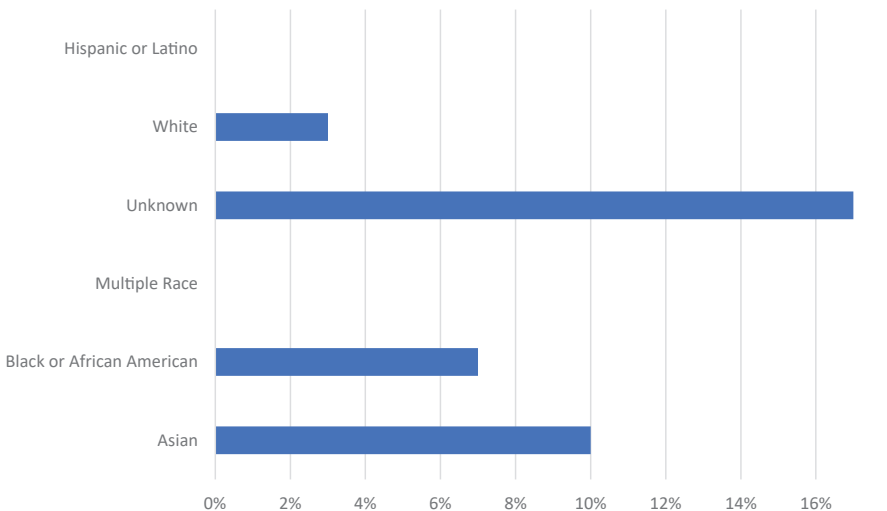


Fig. 4. Challenges with internet access by race and ethnicity.

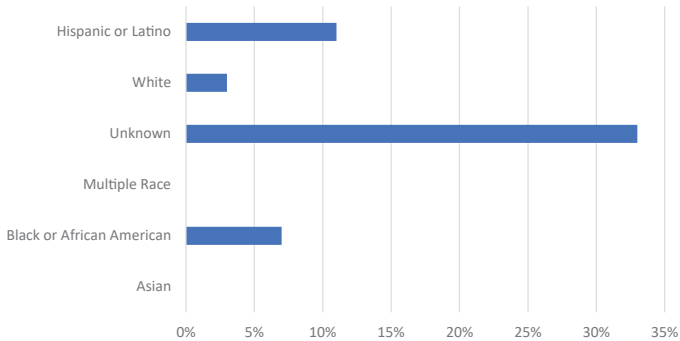


Fig. 5. Challenges with access to a telehealth suitable device by race and ethnicity.

Overall, challenges with MyChart access were the most frequent telehealth challenge identified. This knowledge is important for providers. In many institutions connecting patients and families to resources to assist with access can be done while patients are seen at their in-person visits. The responses for identifying challenges with MyChart varied from other accessibility challenges. Nine percent of white respondents identified challenges with MyChart access while only 5% of black respondents endorsed that accessing MyChart was a challenge.

A total of 18 of respondents had interpretive services scheduled to assist with their video visit. The most frequently assigned was to interpret for those families with an identified hearing loss. This was followed by interpreters for families where Spanish was their primary language. According to the recorded data, only 4 of the families used interpretive services during their telehealth session. It is not known whether the interpreter was not available, the family declined use of interpretive services or if the information on use was omitted in the electronic medical record.

The challenges experienced by the patients in this institution are similar to those discussed in the literature. Also similar to the literature was the overall response from the

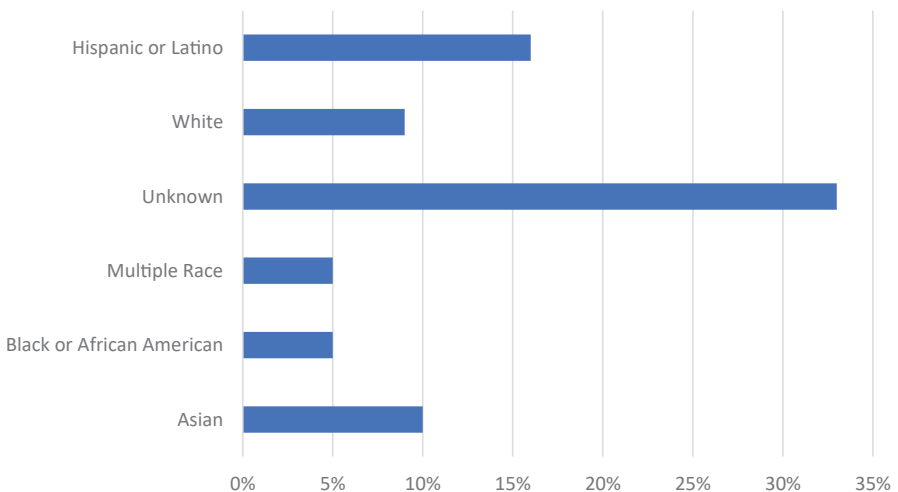


Fig. 6. Challenges logging into MyChart by Race and Ethnicity.

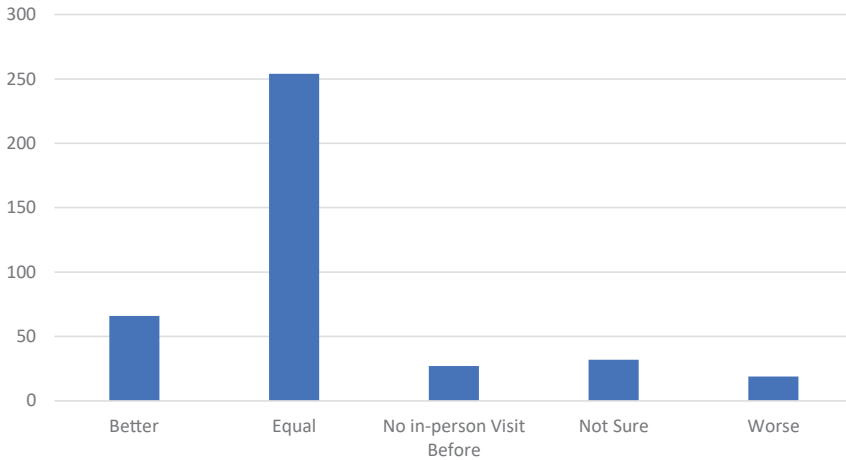


Fig. 7. Count of telehealth compared to in-person visit.

survey respondents as favorable to telehealth use in the future. Telehealth education may need to be a routine component of anticipatory guidance to assist children with NDD and their families with continued telehealth use. Advanced preparation on its purpose and use may decrease accessibility issues. Continued use of telehealth may save families valuable time and money when a telehealth appointment is deemed appropriate for the visit purpose.

LIMITATIONS

An important limitation of this review was the distribution of the survey itself. The survey was sent electronically through email. It is not known if some patients using telehealth were accessing broadband from a location other than their own home. If broadband access was intermittent, the persons experiencing the most challenges may have had limitations in accessing the survey.

Similarly, persons needing interpretive services may have had trouble completing the online survey. This is also true for persons with literacy challenges and may

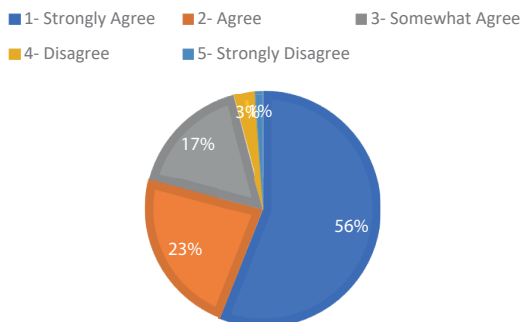


Fig. 8. Family would use video visits in the future.

account for some of the gaps. Connection to interpretive services were made available during the telehealth visit when possible.

The number of incomplete surveys also contributed to the limitations of this project. There were no attempts at in-person completion of surveys secondary to the response to COVID-19. Future projects may utilize both email and in-person completion to capture the responses of those who had difficulty with completion for any reason.

The patients seen in the involved clinics have complex medical needs and represent a small segment of the general pediatric population. The responses from a broader or more homogenous population may yield different results.

SUMMARY

Telehealth use has increased exponentially since the start of the pandemic. For children with complex medical conditions including a neurodevelopmental diagnosis, telehealth provided a safe connection to their frequent healthcare appointments in a time of uncertainty. Telehealth will not disappear as the world transitions from the crisis presented by COVID-19. It is important that clinicians in both clinic-based and hospital settings examine the response from the patients in their community.

The overall response to telehealth in this institution was positive. However, different people will have different experiences. Patients were able to utilize telehealth but experienced some challenges. Ongoing evaluation is needed to improve telehealth models of care and delivery. Increased awareness and understanding of the impact of social determinants of health are also needed to provide equitable, not equal care to this vulnerable population. Use of telehealth will require an evidence-based, team approach to telehealth assessment and to connect patients with resources for success.

CLINICS CARE POINTS

- Use images to assist with communication barriers
- Utilize inclusive intake processes to ask about technology access²¹
- Consider closed captioning options for persons with hearing impairment
- Identify community resources that offer free internet access
- Permit patients to access telehealth from any safe, physical location to decrease barriers to access¹⁵
- Provide guidance on telehealth visits at an in-person visit

DISCLOSURE

There are no financial conflicts of interest to disclose.

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